



**THOMAS L. GARTHWAITE, M.D.**  
Director and Chief Medical Officer

**FRED LEAF**  
Chief Operating Officer

COUNTY OF LOS ANGELES  
DEPARTMENT OF HEALTH SERVICES  
313 N. Figueroa Street, Los Angeles, CA 90012  
(213) 240-8101

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TO: Each Supervisor

FROM: Thomas L. Garthwaite, M.D.   
Director and Chief Medical Officer

Jonathan E. Fielding, M.D., M.P.H.   
Director of Public Health and Health Officer

SUBJECT: **HIV REPORTING**

This is to provide you with the Department's recommended position regarding HIV reporting. In 1999, the Department formulated a position following a review of the literature, current practice and Centers for Disease Control and Prevention (CDC) guidelines. At that time the Department supported confidential reporting of HIV using a name-based system. California initiated HIV reporting using a code-based system in July 2002.

Following intensive review of the more recent studies examining HIV reporting systems and an assessment of the performance of the current code-based system in Los Angeles County, the Department again supports the use a name-based system for HIV reporting. Currently 36 states report HIV using name-based systems. The attached position paper provides an overview of HIV surveillance and the rationale for the Department position supporting confidential name-based HIV reporting.

Both the Public Health Commission and the Commission on HIV Health Services currently support a name-based HIV reporting system. The California Performance Review has recommended a name-based system for California as well.

Implementation of name-based HIV reporting will require State legislative action. Therefore, the Department will work with the CAO to develop a legislative position for Board approval, in support of name-based HIV reporting.

If you have any questions or need additional information, please contact either of us.

TLG:JEF:aml  
tgjfes082604 mem

Attachment

c: Chief Administrative Officer  
County Counsel  
Executive Officer, Board of Supervisors

# Los Angeles County Department of Health Services

## Position on HIV Surveillance

August 2004

### Introduction

The mission of the Los Angeles County Department of Health Service (DHS), Public Health (PH) is to safeguard and improve the health of the County's residents. Preventing the spread of disease, assessing the need for services, and assuring treatment of those with conditions such as HIV and AIDS are essential functions of PH.

Recent advances in the treatment of HIV and AIDS have changed the course and prognosis of the disease. Early detection and treatment of HIV have been shown to have a positive and often dramatic effect on the length and quality of life for those infected and on reducing new HIV transmissions. Recent declines in AIDS deaths are one indicator of the impact of these new treatments. The number of AIDS deaths in Los Angeles County dropped by 61 percent between 1996 and 2001 and AIDS cases decreased by 43 percent for the same period [1]. The net effect is an increasing number of individuals living with HIV/AIDS.

### HIV Reporting Background

Currently, 36 states report HIV by name; one state allows reporting by either name or code; and the remaining states report by code or name-to-code systems [2]. Pennsylvania has a name-based HIV reporting system, except for Philadelphia, which reports HIV cases by code.

In California, HIV reporting by code was initiated on July 1, 2002. The code consists of four elements, Soundex (an alpha-numeric code based upon last name), 8-digit date of birth, a one-digit code for gender, and the last four digits of Social Security Number. Laboratories are required to create a non-name code from the patient-identifying information submitted by the provider to the lab on the HIV test requisition.

The California HIV reporting system is a dual reporting system in which reports are required from both laboratories and providers. Laboratories are required to submit laboratory notifications of confirmed HIV diagnostic tests to the provider and to the local health department in the jurisdiction where the health care provider is located. Upon receipt of a positive HIV test result, the provider is required to document the HIV case in a cross-reference log, and submit an HIV case report by coded identifier within 7 days of diagnosis. All information collected on HIV/AIDS case reports, including the personal identifying information obtained when a person is reported with AIDS, is transferred monthly to the State Office of AIDS in digital format. **In contrast, personal identifying information - such as name, address, and Social Security Number - is not transmitted to any federal agency, including the Centers for Disease Control and Prevention (CDC).**

Upon implementation of the new HIV reporting law, the HIV Epidemiology Program (HEP), the local Public Health program charged with implementing the HIV/AIDS reporting system, estimated that approximately 26,000 persons living with non-AIDS HIV disease in Los Angeles County (LAC) were seeking care for HIV and would be reported as cases of HIV disease under the new surveillance system. As of May 31, 2004, 10,526 cases of HIV have been reported in LAC and an additional 12,073 suspect cases are pending investigation. Suspect cases represent unduplicated laboratory notifications that do not match existing cases in the HIV/AIDS registry.

### **AIDS Surveillance in Los Angeles County**

AIDS cases have been confidentially reported, by name, to the Health Officer of Los Angeles County since 1981. AIDS case data portray the most advanced stage of HIV disease, which tends to develop many years after initial infection. Consequently, the current AIDS surveillance system only provides a retrospective view of the HIV/AIDS epidemic. As the treatment of HIV evolves, it is anticipated that even longer periods will be observed between initial HIV infection and the development of AIDS, further limiting the utility of AIDS case data to derive information about HIV infection. Under the current surveillance system the true magnitude of HIV infection in Los Angeles County can only be estimated.

Planning, program development, and resource allocation depend on data accurately reflecting the number and demographics of persons living with HIV and AIDS. Better estimates of persons living with HIV infection are crucial for comprehensive program and service planning, resource allocation, and evaluation of program and service effectiveness.

**DHS believes that HIV reporting is an essential tool in HIV surveillance.** HIV reporting is superior to reliance on AIDS case data as the primary source of data about the HIV/AIDS epidemic for several reasons, as outlined in the Department's 1999 Position on HIV:

- (1) *HIV reporting provides more accurate information needed to develop and evaluate HIV prevention programs and services.* Data regarding HIV infection is critical to the development and implementation of HIV prevention programs. Detailed information about rates of new infection among high risk groups facilitates the development and implementation of prevention programs addressing the specific needs of these populations. Rates of new HIV infection are also indicators of the effectiveness of prevention efforts.
- (2) *HIV reporting provides more timely information regarding the HIV epidemic.* Due to treatment advances, AIDS data is increasingly limited as a primary source for obtaining estimated numbers of new infections.

HIV reporting provides information about the number of new infections as they occur and

as they are diagnosed. Rather than counting AIDS cases once individuals have progressed to this advanced stage of HIV disease, HIV reporting allows the tabulation of HIV positive persons shortly following testing. HIV reporting provides an estimate of HIV infection that is independent of both progression to AIDS, and delay in seeking treatment following HIV test results.

- (3) *HIV reporting provides better information about HIV infection in our diverse populations enhancing our ability to perform critical public health assessment and assurance functions. Public health must be able to accurately assess the magnitude, scope, and trends of the HIV epidemic. In addition, public health must work to assure that the prevention programs implemented are effective in reducing new infections. Both of these critical functions require accurate and timely data.*
- (4) *HIV reporting provides information about where services are needed. In addition to providing information about new infections for planning prevention services, HIV reporting also provides local health departments and states with better estimates for planning services for those with HIV infection, such as early intervention and case management programs.*
- (5) *Estimates of the numbers of individuals infected with HIV are used to support requests for funds for programs and services from state and federal agencies. HIV reporting provides more accurate estimates of the actual HIV/AIDS burden. Different rates of progression to AIDS, variation in seeking services, and advances in HIV therapy complicate the task of determining the minimum number of persons with HIV infection. HIV reporting provides more accurate estimates of the magnitude of HIV infections and helps assure that sufficient resources are requested to address needs for HIV/AIDS programs and services. HIV reporting provides states with the ability to target their prevention programs to areas and populations where rates of new infections are highest.*

Note that any HIV reporting system will also have limitations – that is, it will only reflect those persons who have been tested for HIV. CDC estimates that 25% of persons living with HIV and AIDS are unaware of their status [3]. This limitation may introduce a reporting bias if certain groups tend to be diagnosed much later in their disease than others do.

### **Name-Based versus Code-Based Confidential HIV Reporting**

While the need for enhanced surveillance is generally agreed upon by a significant proportion of the HIV/AIDS community, community-based organizations, and health care providers, there is disagreement regarding the best methodology for conducting HIV surveillance. Disagreements revolve around two major questions: “Is named reporting a deterrent to HIV testing?” and “Is code-based HIV reporting as good as name-based reporting?” Both issues are discussed below.

### **Is Named Reporting a Deterrent to HIV Testing?**

There is a concern that confidential HIV reporting that includes names will have a significant adverse impact by reducing HIV testing among those most at risk. Specifically, it is argued that men who have sex with men, injection drug users, and other disenfranchised populations (such as homeless and undocumented persons) may be less willing to be tested for HIV if they know that a name-based system of reporting is in place, even if anonymous testing is available. Examples of these concerns follow:

- Burris summarizes earlier studies (from 1985 – 1996) that found mostly high proportions of perceived barriers to HIV testing and unwillingness to be tested if name-based reporting were hypothetically required [4].
- The Gay and Lesbian Medical Association produced a policy statement in 1997 urging caution implementing an HIV surveillance system because: discrimination against HIV infected persons still exists, confidentiality cannot be assured; an HIV surveillance system will not fully represent the epidemic (because it will not include infected persons who have not tested); and it is not needed to track the epidemic [5].
- In a 1999 article by Woods *et al*, 63% of 42 high-risk repeat testers interviewed at a San Francisco counseling and testing site stated that they would forego testing if name-based reporting was required [6]. Important study limitations include: a small number of participants; less than half of eligible persons participated; and the men may have assumed that no anonymous testing would be available if named reporting were required.
- A Colfax and Bindman commentary in 1998 describes the concerns of name-based HIV reporting (information could be used to harm infected persons and fear of being reported may deter infected persons from getting tested) and concluded that “existing observational studies have typically been small and have not controlled for potential confounders” [7].

In response to the concerns that name-based reporting would deter people from testing, CDC funded multiple sites to conduct investigations of the impact of HIV reporting by name on the use of HIV testing in publicly funded counseling and testing programs. Persons at risk for HIV were recruited from various venues and asked about their HIV testing history, knowledge of state HIV reporting laws, and reasons for delaying or not seeking HIV testing. This CDC-sponsored HIV Testing Survey (HITS) was conducted in several phases. The first HITS survey was conducted in nine states from 1995 - 1996 [8], while HITS II was conducted initially in 7 states from 1998 – 2000 [9]. Results from various studies are presented below.

- Nakashima *et al* analyzed service provision data among 459,000 testers at 227 sites in 6 states (LA, MI, NE, NV, NJ, and TN) 12 months before and 12 months after implementation of named HIV reporting and found no deleterious effect on testing at publicly funded counseling and testing programs [10].
- Another study by Hecht *et al* found that knowledge of local policies regarding HIV testing was low **and** did not significantly impact decisions to be tested for HIV for 2,404 high-risk participants; results from named-based HIV reporting states did not differ significantly from

those in code-based reporting states [11].

- San Francisco Department of Public Health conducted the HITS study in 2001, before the implementation of code-based HIV surveillance [12]. Fear of name-based reporting was infrequently cited as a deterrent to HIV testing among the 337 MSM, injection drug users (IDU), and high-risk heterosexuals. Only 2 (both IDU) cited named reporting as a reason to forego testing and none cited it as their main reason.
- Findings from the HITS II study agree with findings in HITS I. Adams et al found that in Oregon, one of 49 HITS I study participant and none of 52 HITS II participants mentioned name-based reporting as a main reason for avoiding HIV testing [13].
- In New Mexico, HIV reporting policies were also found to have little effect on decision-making regarding HIV testing [14]. While 10 of 44 HITS I participants cited named reporting as a reason for not undergoing testing, only 2 of 49 untested HITS II participants agreed.
- In Los Angeles, HIV Epidemiology Program conducted the HITS study in 2002, shortly after HIV reporting was implemented. Men who have sex with men (MSM), heterosexuals (HET), and injection drug users were sampled. Findings were consistent with HITS studies above. Ironically, study participants who believed HIV cases in California were reported by name were less likely to delay or avoid HIV testing compared to participants who thought names were not reported [15].

The findings of all the most recent studies suggest that, among high risk populations, knowledge of state HIV reporting policies was low and that the most common deterrents to testing were the fear of receiving a positive HIV test result and lack of perceiving themselves as being at risk for HIV infection. Further, unlike the results from earlier studies that asked hypothetical questions of their participants (a less valid methodology than observing actual behavior), the newer studies provide little evidence that name-based HIV reporting significantly delays or deters high-risk individuals from testing.

### **Is Code-based reporting as good as Name-based reporting of HIV?**

The concern regarding HIV reporting systems using coded identifiers is that these systems, while feasible [16], have been found to be less reliable and efficient.

In 1994, Maryland and Texas were the first states to implement code-based HIV surveillance systems. Upon implementation, they participated in a 3-year collaboration with the CDC to evaluate their reporting systems [17]. Evaluation criteria included code completeness, timeliness of reports, and potential for matching codes to alternate databases. In Texas, the ability to trace back coded reports to patient records was evaluated and, in Maryland, provider compliance with maintaining the cross-reference logs was assessed.

Of 9,971 HIV infection reports entered in Maryland during evaluation, all essential code

elements were present on 71% of reports; only 44% of providers maintained the cross-reference log; completeness of reporting was estimated at 50%, and median report delay was 20 days.

Of 16,119 HIV infection reports entered in Texas during evaluation, all code elements were present on 62%; completeness of reporting was estimated at 26%; median report delay for batched reports was 173 days and 59 days for non-batched reports. Only 60% of case notifications could be matched to a client record demonstrating the difficulty of epidemiologic follow-up. Cross-reference logs were not required.

The authors concluded that while both systems demonstrated timely reporting, 22 percent of reports in Maryland and 34 percent of reports in Texas were incomplete due to missing social security numbers. In addition, coded identifier procedures hampered the collection of vital risk assessment information.

A subsequent evaluation of Maryland's HIV reporting system was conducted after the four years of data collection [18]. In this evaluation, conducted by Maryland health officials, they concluded that when complete, the code used in their state provided an excellent unduplicated case count with 99.8% unique cases. However, when the code was not complete, such as the 37.6% of cases missing the last four digits of SSN, a less than adequate 77% of records were unique.

Based on these and other studies, CDC concluded that the use of coded-identifiers limits the performance of the surveillance system and complicates epidemiologic follow-up to obtain case data, resulting in CDC's recommendation for states to do named-based HIV reporting in their 1999 HIV surveillance guidelines [19].

### **Code-based Reporting in Los Angeles County**

Since 1999, when DHS issued its first statement regarding HIV reporting, we have had two years to examine the code-based system in Los Angeles County. Our examination reveals several serious concerns with code-based HIV reporting, some of which are consistent with concerns raised in CDC's 1999 surveillance guidelines cited above:

- 1) **There is a backlog of cases pending investigation.** After two years of HIV surveillance, the number of unmatched laboratory notifications identified each month routinely exceeds the number of HIV cases reported monthly. As such, the HIV Epidemiology Program (HEP) is unable to estimate when it will attain complete reporting of HIV prevalent cases. As noted earlier, over 12,000 suspect cases are pending investigation. The one-time allocation of resources used for the retention of temporary HEP staff to assist with case surveillance and data management will terminate in September 2004. This reduction in staff will jeopardize local HIV surveillance efforts since the number of new cases HEP will be able to investigate and report will decline significantly after September 2004.
- 2) **Current HIV surveillance data are not representative.** HEP has not been able to conduct active surveillance at all sites where cases have been identified and there are

some high-prevalence sites where completeness of reporting is less than 25%. These sites have cited having difficulties in complying with the non-name code reporting requirements as a reason for not being able to report.

- 3) **Code-based reporting is extremely labor intensive.** HEP estimates that compared to AIDS case investigations, HIV case investigations take twice as much time to complete. A primary difficulty in code-based HIV surveillance is the failure of providers to keep the mandated cross-reference log that is intended to link the code to the patient identifying information. Less than one-third of providers are maintaining a log. Without the log, field surveillance staff must search through multiple case files to identify the appropriate medical record. Further, data management is more labor intensive due to the considerable staff time spent eliminating thousands of duplicate lab notifications each year.
- 4) **Coding errors on laboratory notifications are common.** Although not yet systematically documented, errors in the Soundex, date of birth, and gender codes are common. For field surveillance staff, these errors increase the difficulty in obtaining the appropriate medical record for review and translate into many wasted hours looking for cases that do not exist or have already been reported. For data management staff, code errors increase the likelihood of false matches and false non-matches. (A false match occurs when the code on a laboratory notification or case report is identical to that of a case that has been reported previously, but is in fact a unique case that has not been reported. A false non-match occurs when the code reported does not match any previously reported cases, but is in fact a case that has been reported previously.) CDC requires that HIV/AIDS surveillance systems perform case matching with  $\geq 95\%$  accuracy. Though not yet quantified, in HEP's experience investigating HIV cases for the past two years, the code performance for false non-matches seems to be far below 95%.
- 5) **Cross-reference logs risk patient confidentiality.** The cross-reference logs pose a risk to the confidentiality of patient information if not stored securely. To date, two providers have misplaced or lost their cross-reference logs. Further, HEP has concerns about the long-term storage of these logs at health care sites. For these reasons, we believe that site-specific HIV case logs pose a greater risk to the confidentiality of HIV case information than does a name-based registry maintained by the local health department.
- 6) **Plans for a comprehensive evaluation of the surveillance system have been scaled back.** The California State Office of AIDS (SOA) had planned a comprehensive multi-county 18-month evaluation of the surveillance system beginning July 1, 2004. The evaluation would have closely followed the methodology recommended by the CDC for evaluating HIV/AIDS surveillance systems, including a capture-recapture assessment measuring completeness of reporting and an evaluation of false matches and false non-matches. Due to funding restrictions and staffing constraints, the SOA plans to limit the evaluation to descriptive methods only. It is unlikely that this scaled-back evaluation plan will be sufficiently rigorous to satisfy federal requirements. As such, statewide HIV surveillance data are likely to remain unincorporated into national HIV/AIDS surveillance summaries and future allocations of Ryan White Care Act and CDC Prevention funding

may be jeopardized.

- 7) **Future HIV/AIDS funding will be linked to HIV surveillance.** Estimates of the numbers of individuals infected with HIV will be used to support the allocation of State HIV/AIDS resources beginning July 2005 and federal HIV/AIDS resources beginning March 2007. Since HIV reporting provides more accurate estimates of the actual HIV/AIDS burden in a jurisdiction, ensuring its accuracy – particularly as the most impacted jurisdiction in the State and second most impacted jurisdiction in the country – will prove crucial to ensuring adequate funding levels. A shift to a name-based reporting system will improve the accuracy of local HIV/AIDS surveillance, improve the efficiency of case surveillance activities, and place Los Angeles County more competitive position for funds that support HIV care, prevention and other disease control activities, including epidemiologic surveillance.

## **Security and Confidentiality of HIV and AIDS Case Surveillance in Los Angeles County**

Persons living with HIV and AIDS have been beset with significant social stigma, thereby fostering serious concerns regarding the confidentiality and disclosure of HIV-related information. These concerns continue to persist, especially as HIV and AIDS become more prevalent in groups that have historically been economically and/or socially disenfranchised. Sensitivity regarding a diagnosis of HIV or AIDS and associated fears regarding employment, housing and other forms of discrimination cannot be minimized. It is essential that the confidentiality of all sensitive health data be maintained and protected.

Los Angeles County has maintained an AIDS surveillance system since 1981, involving the confidential reporting of names and personal identifiers of over 48,000 individuals diagnosed with AIDS. Experience with AIDS reporting has demonstrated high standards for the protection of confidential data. It is important to note that, in the 23 years of operation of this system, there has been no known breach of confidentiality or inappropriate disclosure of these sensitive data.

In Los Angeles County, once a person with HIV enters treatment they are no longer anonymous within the health care setting. In fact, the HIV status of individuals in treatment is maintained confidentially in service-related databases, such as those maintained for the AIDS Drug Assistance Program (ADAP), the federally-funded MediCal program, the Ryan White Care Act client database, and other insurance databases.

DHS remains committed to protecting the confidentiality of those with HIV and AIDS as a part of its public health charge. The Department is particularly cognizant of the sensitivity of some individuals and groups, such as undocumented residents, who may wish to remain anonymous when seeking HIV testing. DHS believes that options for voluntary, anonymous testing must be maintained and is committed to guaranteeing access to anonymous testing as an alternative choice for those reluctant to utilize confidential HIV testing services.

## Summary

A review of the available information regarding HIV surveillance has revealed that there are compelling reasons to implement name-based HIV surveillance in Los Angeles County. Name-based HIV reporting would facilitate the characterization of HIV infection in Los Angeles County, help the Department identify emerging trends in the epidemic, and facilitate better targeting of programs and services.

While name-based surveillance may present barriers to those at risk of HIV infection, recent studies indicate that these barriers are minimal. The provision of accessible anonymous testing provides an important alternative for those who are reluctant to utilize confidential HIV testing services. When combined with stringent laws regarding the confidentiality of HIV data and public information and education regarding these safeguards, the number of individuals reluctant to receive confidential HIV tests should be minimized.

As the epidemic changes, due to improvement in HIV therapy, our methods of surveillance must provide us with the best information regarding the extent and distribution of HIV in our County.

Based on our experience with the current code-based system, the successful use of confidential name-based reporting systems for other reportable diseases in Los Angeles County, and positive outcomes in other jurisdictions that have adopted name-based HIV surveillance, **DHS views HIV confidential reporting using a name-based system as the most effective, efficient, and reliable method of conducting HIV surveillance.**

## **DEPARTMENT POSITION**

- DHS supports the confidential reporting of HIV using a name-based system as the method of choice for HIV reporting.
- The Department of Health Services (DHS) supports the confidential reporting of HIV infection to the County Health Officer for the purposes of HIV surveillance in recognition of the importance of this information in prevention, planning, resource allocation, and evaluation activities.
- The County should enlist Legislative Advocates to explore strategies and identify legislation sponsors to convert California's HIV surveillance system from a code-based to a name-based system.
- DHS supports and recommends the promotion of confidential HIV testing that allows for follow-up with non-returning HIV-positive testers complemented by anonymous testing alternatives for those reluctant to test due to HIV reporting requirements.
- DHS supports and recommends the strengthening and expansion of community-based, voluntary partner notification. This would include the expansion of voluntary partner notification programs making services available to clients in both public and private settings.
- DHS supports and recommends the strengthening and expansion of early intervention programs and recommends the expansion of the federal AIDS Drug Assistance Program to assure early assessment and treatment of persons living with HIV infection.
- DHS supports and recommends increasing availability and accessibility of HIV and AIDS services to assure that persons living with HIV and AIDS are able to utilize medical, health and support services.
- DHS supports and recommends that County legislative advocates work to strengthen existing laws to prevent discrimination against persons living with HIV and AIDS

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